Brief Report

Policy Brief: The Necessity of Developing a Population-Based Asthma Registry System in Khuzestan Province

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Abstract

Khuzestan Province faces significant air quality challenges, ranking among Iran's most polluted regions. This stems from a combination of unique climatic conditions, industrial and agricultural emissions, and the persistent influx of fine dust from both domestic and international sources. As a result, air quality in the province's urban centers is frequently unhealthy for sensitive groups and often for the general population. These conditions have contributed to a marked increase in respiratory ailments, such as asthma. A critical policy gap exists: Decision-makers currently lack robust, systematic, population-level data to understand the full scope of this public health crisis, identify high-risk groups, and evaluate the effectiveness of interventions. Establishing a population-based asthma registry is essential to fill this information void. Such a system would provide healthcare authorities with the evidence base needed to identify underlying risk factors, track disease-related complications, and assess the impact of various therapeutic and preventive measures. Beyond advancing medical research, the data generated would be instrumental in supporting evidence-based decision-making and targeted policy development within the healthcare system. Specifically, insights from this registry would provide critical evidence to inform national health priorities and strategic resource allocation, guiding investments in prevention, specialized care, and infrastructure for respiratory health across Iran. This policy brief outlines the key challenges and proposes strategic actions for the successful implementation of an integrated asthma registry.

Keywords: Asthma, Registries, Khuzestan, Health Policy

1. Background

Asthma, a chronic inflammatory disease of the airways, is a major global health concern that affects approximately 300 million people worldwide and causes around 1,000 deaths each day. The majority of these deaths occur in low- and middle-income countries, and most are preventable (1). Preventable mortality from asthma continues to occur largely due to inadequate disease management, particularly the overreliance on reliever medications instead of preventive (controller) therapies — an issue that must be urgently addressed (2). Beyond mortality, asthma significantly impacts individuals' work, education, and family life, with especially profound consequences when children are affected. Moreover, the prevalence of asthma is rising in many developing countries undergoing economic transition, and the associated healthcare costs are steadily increasing, imposing a growing burden on health systems, communities, and individuals. The overarching goal of asthma management at the population level is to prevent mortality and minimize the burden of the disease on individuals, families, communities, healthcare systems, and even the environment (1).

However, effective prevention and treatment require robust evidence derived from medical research, national and international reports, and other reliable

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health information sources. Disease registries are among the most widely recognized infrastructures worldwide for systematically collecting data to support medical research and inform policymaking in chronic disease management. This policy brief analyzes the current status of the asthma registry initiative at Jundishapur University of Medical Sciences in Ahvaz, identifies key challenges and barriers to its implementation, and offers recommendations for developing and launching an integrated population-based asthma registry in Khuzestan province.

2. Problem Statement

Khuzestan province, with a population of nearly 5 million, is the fifth most populous province in Iran. Covering an area of approximately 64,057 square kilometers, it is one of Iran's major industrial, oil, and agricultural hubs (3). Over the past four decades, the province has faced numerous environmental crises. These include the aftermath of the eight-year war with Iraq (4), pollution from the two Persian Gulf Wars in southern Iraq and its impact on Khuzestan (5), drought in neighboring Iraq (which shares a border with Khuzestan), contamination from the expansion of steel, oil, gas, and sugarcane industries (6, 7), and the phenomenon of particulate matter (dust storms) (8). These climatic and industrial conditions have led to a sharp increase in air pollution indices and, consequently, a significant rise in the prevalence and severity of respiratory diseases such as asthma, chronic obstructive pulmonary disease (COPD), and bronchitis (9). Among these, asthma is particularly prevalent, and air pollution can profoundly exacerbate its symptoms and influence treatment response. Based on some studies, the prevalence of asthma and asthma-like symptoms in Khuzestan province is twice the national average in Iran (10). Conducting research on the prevention and treatment of asthma, as a chronic respiratory disease, requires a systematic framework for patient identification, timely treatment initiation, and continuous follow-up (11).

One strategy for the ongoing monitoring of asthma patients is the use of integrated health information systems, such as electronic medical records (EMRs) or the electronic health record (EHR). However, in Iran, despite nearly two decades of planning by the Ministry of Health for the Iranian EHR project, a fully realized EHR system has not yet been implemented (12). Furthermore, policies in the domain of e-health reveal significant shortcomings and a failure to achieve established goals (13). While an integrated electronic system like an EHR would facilitate access to patient medical histories, enable treatment process monitoring, improve communication among healthcare teams, and enhance patient engagement in self-management (14), its absence not only complicates data collection but also negatively impacts the quality of patient care. Given the lack of infrastructure such as EMRs or EHRs for managing treatment and recording data for asthma patients, a practical alternative is the establishment of a disease registry. Crucially, this addresses a fundamental policy gap: Decision-makers currently operate without a comprehensive, population-level evidence base specific to asthma in high-risk regions like Khuzestan. They lack reliable data on disease burden trends, the real-world effectiveness of clinical guidelines, the socioeconomic impact of asthma, and the return on investment for public health interventions. Implementing a population-based asthma registry provides a valuable opportunity to determine disease incidence and prevalence, identify underlying risk factors, investigate disease complications, and evaluate the effectiveness of various treatment interventions. This data creates a vital resource not only for medical research but, more importantly, to enable evidence-based decision-making and targeted health policy formulation (11), filling the critical information void that currently hinders effective public health action.

3. Context and Current Situation

The Hospital-Based Asthma Registry was launched in 2019, coordinated by the Imam Khomeini (RA) Educational, Therapeutic, and Research Center at Ahvaz Jundishapur University of Medical Sciences. The program's objective is to identify patients with asthma and systematically collect data on their medical history, signs and symptoms, exacerbating factors, diagnostic tests, disease severity, administered treatments, and response to therapy. Data collection is conducted using standardized questionnaires for asthma and comorbid conditions — including allergic rhinitis, skin allergies, and obstructive sleep apnea — via a web-based software platform developed by the university's Statistics and Information Technology Management engineers. According to the registry protocol, patients who meet the inclusion criteria are enrolled as new cases. An electronic file is created for each patient within the registry software, where all visit-related information is recorded. The software is configured to generate outputs in a format suitable for statistical analysis.

Quality control checks on the registered data are performed periodically (every three months).

To date, data from 1,500 asthma patients have been registered. Following data quality control, an Excel output of the data is prepared. The data are then coded and imported into SPSS software. Depending on the research objectives, the study protocol utilizes descriptive statistics and inferential statistical methods. The statistical analysis is performed by a member of the steering committee who specializes in biostatistics. An analysis of this data revealed the following key findings:

1. Over half of the asthma patients were female.

2. Approximately one-quarter of the patients had a history of emergency department visits or hospitalizations due to asthma attacks.

3. Nearly one-fifth of the patients were in poor economic circumstances.

4. Given the long intervals between exacerbations and their seasonal pattern in most patients, the primary problem in Khuzestan appears to be significantly associated with seasonal asthma.

5. A considerable number of patients also suffered from other allergies. Poor control of allergic rhinitis played a significant role in both the onset and poor management of asthma symptoms.

6. For some patients, the disease significantly impacted their daily activities, leading to reduced social participation.

7. The use of paraclinical methods (spirometry) and the investigation of disease phenotypes — which are highly effective in disease management — were underutilized by physicians relative to their clinical necessity.

8. Anxiety and depression were highly prevalent among the patients, negatively impacting disease control and leading to reduced functional capacity.

4. Challenges and Barriers

4.1. Infrastructure Limitations

In Iran, despite the implementation of the SEPAS project (the Iranian EHR system), a fully operational EHR comparable to those in developed countries is not yet available. An EHR, by systematically compiling all of a patient's medical history — including symptoms, risk factors, pulmonary function test results, medications, hospitalizations, outpatient visits, and disease-related complications — provides a rich and accessible database for monitoring diagnosis, treatment, and follow-up. This integration of information not only assists physicians in planning diagnostic and therapeutic interventions but also enables researchers and health policymakers to examine disease progression and the effectiveness of various treatments. The lack of access to a functioning EHR imposes significant constraints on patient follow-up and limits the effectiveness of disease registry systems.

4.2. Underreporting of Patients

One of the most significant challenges in implementing hospital-based registries for asthma and similar conditions is the high rate of missing cases. Several factors contribute to this problem:

- A considerable proportion of patients are outpatients who may never visit the hospitals designated as data collection sites during the registry period.

- Only a small number of physicians, typically members of the registry's steering committee or direct collaborators, are actively involved. Consequently, if patients are treated by specialists outside the program, they are not included in the registry.

- In Khuzestan province, there are five independent medical universities. Many patients bypass the referral system and directly seek care at Imam Khomeini University Hospital, the main tertiary center, thereby complicating registry coverage.

- Numerous patients, especially those in rural or peri-urban areas, may not consult specialists despite having asthma. General practitioners (GPs) often lack access to advanced diagnostic tools, resulting in underdiagnosis or missed opportunities for specialized care.

- In many cases, patients are not referred from primary care or even from specialist-level care to subspecialty centers, despite clear indications.

As a result of such underreporting, valuable information from a substantial proportion of patients is lost, making it impossible to accurately calculate disease incidence and prevalence.

4.3. Patient Follow-up Challenges

Patient follow-up is of particular importance in asthma management, yet recording follow-up data faces multiple obstacles:

- Due to cultural, economic, and infrastructural issues, patients' follow-up visits are inconsistent and do not adhere to a defined schedule. A patient may not return to the same physician or may seek care from providers outside the registry.

- In the absence of an EHR, comprehensive documentation of the treatment process throughout the study period is not feasible. Data are only recorded when the patient visits the designated physician and provides the necessary information. Meanwhile, patients may simultaneously receive diagnostic or therapeutic care elsewhere.

- It is common for patients to consult, within short intervals, a GP, an internist, and one or more pulmonology subspecialists. Discrepancies in clinical opinions often lead to changes in prescriptions, including substitutions of medications with similar effects from different pharmaceutical companies.

- Physicians' limited confidence in domestically produced medications, often due to insufficient clinical research, has led to widespread prescribing of imported drugs. This not only imposes significantly higher costs on patients and insurers but also results in considerable currency outflow from the country.

- The GPs are not authorized to prescribe first-line controller medications for asthma until patients are referred to specialty or subspecialty centers. This restriction contributes to recurrent exacerbations and increased emergency visits, particularly among patients in rural and peri-urban areas.

- Inadequacies in medical education also play a role. Training is heavily hospital-based rather than community-based, with limited focus on outpatient and emergency asthma management. Moreover, insufficient instruction on patient education, rational prescribing, and familiarity with the range of drugs available in the national market further complicates effective care and follow-up.

4.4. Difficulties in Data Collection

In most disease registries in Iran, data are collected manually either from primary sources (during patient visits) or secondary sources (such as medical records) before being entered into registry software. Even for electronic data such as laboratory results available in hospital information systems, automated data transfer is often not possible. Consequently, data collection is time-consuming, requires adequately trained staff, and is resource-intensive. This limitation reduces the scope of registry programs, increases data collection costs, lowers case-finding efficiency, and elevates the risk of errors.

4.5. Lack of Evaluation of Disease Impact on Patients' Personal and Social Life

Internationally, the outcomes of diseases are commonly assessed in terms of personal and social consequences using standardized tools, such as the World Health Organization Disability Assessment Schedule (WHODAS 2.0), which measures limitations in activity and participation. In Iran, however, disease registries rarely evaluate disability or functional outcomes in a standardized manner. These challenges underscore the necessity of adopting a well-defined strategy to maximize patient identification, ensure ongoing monitoring of disease progression, and improve treatment follow-up. Strategic recommendations and proposed solutions to address these barriers are presented in the following section.

5. Recommendations and Strategic Proposals

5.1. Establishing a National Asthma Registry System

Given that air pollution remains a major concern in most regions of Iran, and considering the projected increase in asthma incidence and prevalence due to global warming, intensifying drought, and consequently the rise in dust storms, it is recommended that a National Asthma Registry be implemented by the Ministry of Health, similar to the population-based cancer registry program. To this end, with the support of the Deputy of Research and Technology of the Ministry of Health, the following actions are proposed:

- Establishment of a National Asthma Registry Steering Committee within the Ministry of Health.

- Formation of regional and university-level committees (including issuing guidelines and determining committee membership).

- Defining the objectives of the National Asthma Registry.

- Designing a comprehensive protocol for case finding, patient follow-up, data entry into the registry, quality control, and reporting.

- Developing a minimum dataset for the asthma registry.

- Providing organizational infrastructure for the implementation of the registry (e.g., defining the roles of research centers, clinical departments, or relevant deputy offices in medical universities in program implementation, securing and allocating financial resources, and training users).

- Preparing confidentiality, data security, and information dissemination guidelines.

- Developing performance evaluation criteria for universities and collaborating centers in the registry program.

5.2. Designing an Integrated National Asthma Registry Information System

The use of a free, scalable, and unified software platform can significantly facilitate and accelerate the structured collection of patient data. This system should function as an EHR for asthma patients, enabling the documentation of information from diagnosis through treatment completion. Furthermore, it must be interoperable with other national systems, such as electronic prescription platforms, the SEPAS system (Iran's hospital information system), and the national civil registration database (for automatic retrieval of patient demographic data). Essential features of the software should include: Compliance with data exchange standards, application of standardized medical terminologies, availability of open and well-documented APIs, assurance of data security and confidentiality, user-friendliness, and a dedicated mobile application.

5.3. Patient Identification and Referral at the Primary Care Level

One of the main challenges in asthma registry programs is underreporting of patients. Thus, a strategic policy at the primary healthcare level is required. Although the Ministry of Health has piloted an asthma care program in certain regions (e.g., Karun County under Ahvaz Jundishapur University of Medical Sciences), expansion to other health centers has been hindered by existing challenges. The primary goals of this program were to facilitate the detection of suspected asthma cases and to encourage GPs to refer these patients to specialists. A nationwide guideline should therefore be issued for family physicians, rural health center staff, and GPs in private clinics to standardize the detection and referral of asthma patients.

5.4. Engaging Specialist Physicians in the Private and Non-university Sector

It is crucial to design policies that incentivize the participation of specialists practicing in non-university settings in the registry program. Such policies could include: Raising awareness of the registry among targeted specialists and non-university centers; organizing continuing medical education workshops on the national asthma registry; promoting the registry through the Ministry of Health in professional medical forums (e.g., conferences); and awarding annual credit points toward license renewal for participating physicians.

5.5. Leveraging the Capacities of Other Institutions and Organizations

Collaboration with governmental agencies, non-profit organizations, and private companies can enhance both public and professional trust while also providing financial support for the registry. Potential partners include: The Iranian Society of Pulmonology, the Asthma and Allergy Association of Iran, domestic pharmaceutical companies, and organizations linked to air pollution control (e.g., the Environmental Protection Organization, Ministry of Industry, Mine, and Trade, municipalities, Ministry of Energy, and Meteorological Organization). Moreover, industries that contribute to air pollution — such as the National Iranian Oil Company, steel industries, the Sugarcane Development Company, the Carbon Black Company in Khuzestan, and similar enterprises in other provinces — should also be engaged. Polluting industries, such as petrochemical and steel plants, are obligated — as part of their Corporate Social Responsibility (CSR) — to cover a portion of the health-related costs for populations in affected areas. Therefore, funds allocated under CSR frameworks can be used to partly finance the implementation of a population registry system in the province. Regarding other public institutions, such as the Environmental Protection Organization and the Health Insurance Organization, their capacities can be leveraged for implementing the registry program through bilateral cooperation agreements.

5.6. Ensuring Patient Participation in the Registry

The chronic nature of asthma and the need to document its course, outcomes, and impact on patients' personal and social lives cannot be achieved without active patient participation. This can be promoted through patient and caregiver education about the benefits of registry participation and by granting patients-controlled access to their EHRs within the system. Additionally, it is recommended that the registry incorporate a personal health record (PHR) module, enabling patients to complete portions of their data through self-assessment questionnaires.

6. Conclusions

Environmental pollutants — both chemical and biological — combined with the specific climatic conditions of Khuzestan province, are likely to increase the number of asthma cases and exacerbate disease severity among existing patients in the future. Meanwhile, the country's economic situation and the rising costs of healthcare make the management of chronic diseases such as asthma increasingly challenging. The asthma disease registry can play a crucial role in addressing a critical policy gap: It provides the systematic, population-level data that decision-makers currently lack to move from reactive to proactive management. Beyond facilitating medical research, such a registry generates the essential evidence base for informed health policy decisions, enabling targeted interventions, rational resource allocation, and outcome evaluation. Through its patient-centered and systematic data collection approach, it can directly contribute to improving diagnostic accuracy and therapeutic effectiveness. The current asthma registry system at Jundishapur University of Medical Sciences in Ahvaz — one of the few active asthma registry programs in the country — has been established through the efforts of specialists in the field and with the support of university officials, adapting its infrastructure to existing conditions. While serving as a suitable regional model, it nevertheless faces a series of difficulties and challenges, similar to other hospital-based registry programs. Addressing these challenges requires the adoption of strategic policies at both regional and national levels.

Accordingly, to establish a robust information infrastructure for research and policymaking regarding asthma, a series of recommendations have been proposed. These include the development of a national asthma registry by the Ministry of Health and the active engagement of key stakeholders, such as GPs, internal medicine and pediatric specialists, pulmonologists, clinical immunologists, and patients across both academic and non-academic centers. In the absence of a comprehensive national EHR system, the strategies and recommendations outlined in this study can also contribute to the systematic collection of information for other chronic diseases with similar characteristics, thereby helping to close the evidence gap that hinders effective public health policymaking across multiple domains.

Footnotes

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